REPORT

Effective HIV Surveillance Among Asian Americans and Native Hawaiians and Other Pacific Islanders

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National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
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Executive Summary

The three primary goals of the *National HIV/AIDS Strategy* are: 1) reducing the number of people who become infected with human immunodeficiency virus (HIV), 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities. To achieve these goals, the *National HIV/AIDS Strategy's Federal Implementation Plan* calls for efforts to support surveillance activities to better characterize HIV among smaller populations such as Asian Americans (AAs) and Native Hawaiians and other Pacific Islanders (NHOPIs), and calls for the Centers for Disease Control and Prevention (CDC) to provide recommendations on effective HIV surveillance activities to health departments of states with high concentrations of AA and NHOPI populations.

To develop these recommendations, CDC selected 5 states (California, Hawaii, New York, Texas, Washington) and 3 separately funded cities and county within these states (Los Angeles County, New York City and San Francisco) with large numbers of AAs and/or NHOPIs to conduct an assessment of current surveillance practices and identify areas for improvement. As a first step, a literature review was conducted to identify key issues. This was followed by consultations with experts from CDC and other federal agencies, academia, and partner organizations that work with AAs and NHOPIs. Finally, we held assessments with state HIV case surveillance and Medical Monitoring Project/National HIV Behavioral Surveillance System coordinators to gain insight into issues of data collection, analysis, dissemination and use, and identify areas for improvement.

Based on the findings of the assessment and recognizing that some approaches may be applicable in some jurisdictions but not others, we propose recommendations that should be standard practice to improve HIV surveillance among AAs and NHOPIs. We also propose recommended practices that expand on these basic improvements to be implemented where possible.

Recommendations for HIV Surveillance Programs

Standard practice:

1. Collect data on ethnic subgroups of AAs and NHOPIs (e.g., Chinese, Vietnamese, Hawaiian) in addition to data on race.

2. Educate providers on the importance of collecting self-reported information about race and ethnic subgroup for AAs and NHOPIs.

3. Analyze and report data on AAs and NHOPIs separately in routine and special reports ensuring that confidentiality is not compromised and that the data are reliable. Also, present data by ethnic subgroups of these populations when feasible.

4. Present data for AAs and NHOPIs separately from large populations using a scale appropriate for small populations when data for larger population groups might overshadow the data on AAs and NHOPIs in the same chart.

5. Distribute surveillance reports, epidemiologic profiles, factsheets, and newsletters containing data on AAs and NHOPIs to community-based organizations (CBOs) serving AA and NHOPI communities, as well as to other organizations that have expressed a need for information on AAs and NHOPIs.

6. Respond quickly to special data requests related to AAs and NHOPIs.

7. Conduct presentations to HIV planning groups (HPGs), Ryan White Planning Councils, other planning bodies, as well as AA and NHOPI-focused CBOs that use HIV data for prevention and evaluation, including assessing linkage to care, retention in care, and viral suppression.

8. Promote the use of AA and NHOPI surveillance data by providing technical assistance to HPGs and AA/NHOPI-focused CBOs in interpreting the data and using the data to prioritize risk groups for prevention and care programs.

Recommended practice:

1. Match HIV surveillance data with viral hepatitis and TB registries in order to identify co-infection with hepatitis B and TB since both are prevalent among AAs and NHOPIs.

2. Post surveillance reports, epidemiologic profiles, factsheets, newsletters, and slide sets containing data on AAs and NHOPIs on the health department's website.

Introduction

The three primary goals of the *National HIV/AIDS Strategy* are: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities.[1] To achieve these goals, the *National HIV/AIDS Strategy's Federal Implementation Plan* calls for efforts to support surveillance activities to better characterize HIV among smaller populations such as Asian Americans (AAs) and Native Hawaiians and other Pacific Islanders (NHOPIs). In this regard, the Implementation Plan calls for the Centers for Disease Control and Prevention (CDC) to provide recommendations on effective HIV surveillance activities to health departments of states with high concentrations of AA and NHOPI populations.[2]

Accordingly, CDC selected 5 states (California, Hawaii, New York, Texas, and Washington), and 3 separately funded cities and County within these states (Los Angeles County, New York City, and San Francisco) with large numbers of AAs and/or NHOPIs to conduct an assessment of current surveillance practices and to identify gaps/barriers and areas for improvement.

All the selected jurisdictions are funded for HIV case surveillance. Additionally, the selected jurisdictions except Hawaii are funded for the National HIV Behavioral Surveillance System (NHBS) and the Medical Monitoring Project (MMP).

To inform the recommendations, key issues were identified through literature review and assessments were held with state HIV surveillance coordinators, experts in the field, and selected partner organizations. This report provides recommendations for improving HIV surveillance among AAs and NHOPIs in the areas of data collection, analysis, dissemination, and use of data. The report also describes the activities that led to the development of the recommendations.

Background

AAs and NHOPIs are a growing group in the United States. In 2010, 16 million AAs and NHOPIs lived in the United States, representing 5% of the U.S. population,[3] and this proportion is expected to increase to 9% by 2050.[4] AAs and NHOPIs are a heterogeneous group, with many different ethnicities, languages, and cultures, including new immigrants and persons whose families have been in the United States for many years or generations. The majority of AAs (60%) living in the United States are foreign-born, whereas the vast majority of NHOPIs (86%) were born in the United States.[5] AA and NHOPI populations are concentrated in metropolitan areas, such as Los Angeles, San Francisco, and New York City[6]. Twenty-eight percent of AA and NHOPI households are linguistically isolated, with all household members age 14 years and older having at least some difficulty with English.[7] For AA and NHOPI immigrants, issues of poverty, limited language proficiency, and immigration status can be barriers to accessing HIV prevention and care services.[8]

Although HIV prevalence among AAs and NHOPIs remains relatively low compared with other racial/ethnic groups (66.7 and 184.5 per 100,000 population for AAs and NHOPIs, respectively, in 2009[9]), there is evidence

that rates of HIV diagnoses are increasing for these populations. An analysis using data for 2001-2008 from 33 states with confidential name-based HIV infection reporting for at least 4 years found that of all the racial and ethnic groups, AAs and NHOPIs combined were the only group with a statistically significant average annual increase (4.4%) in HIV diagnosis rates (5.1% and 1.9% increase for males and females, respectively).[10] Of AAs and NHOPIs who received an AIDS diagnosis in 1985-2002, 61% were born outside the United States.[8] AAs and NHOPIs have a high prevalence of hepatitis B virus infection, with studies reporting a prevalence of 6%-15%[11,12] in these populations. Of persons infected with HIV, an estimated 10% are co-infected with hepatitis B.[13] Although the number of newly reported cases of tuberculosis (TB) in the U.S. reached an all-time low in 2010, there are still disproportionately higher rates of TB among racial/ethnic minorities.[14] In 2010, the TB case rates for AAs and NHOPIs were 22.4 and 20.8 per 100, 000 population, respectively. The TB case rate for Asians was more than three times the rate for Hispanics or blacks/African-Americans.[14] HIV-infected persons are at high risk for developing TB after infection with *Mycobacterium tuberculosis*. For all ages, the percentage of HIV co-infection in persons reported with TB was 6% in 2009, decreasing from 15% in 1993.[15]

HIV Surveillance Systems

National HIV Surveillance System

Since the beginning of the HIV epidemic in the United States, all U.S. states, the District of Columbia, and the U.S. dependent areas have reported cases of acquired immunodeficiency syndrome (AIDS) to CDC using a standardized system.[16] In 1994, CDC expanded the national surveillance system to include diagnoses of both HIV infection and AIDS, and 25 states with confidential name-based HIV infection reporting began submitting case reports to CDC. Over time, additional areas implemented confidential name-based HIV surveillance and all states, the District of Columbia and 6 dependent areas had implemented such surveillance by April 2008. The 2011 *HIV Surveillance Report* marks the first time estimated numbers and rates of diagnoses of HIV infection have been included from all 50 states, the District of Columbia, and 6 dependent areas. Because states implemented confidential name-based HIV infection reporting at different times, the displayed data on diagnosed HIV infection begin with data from 2008, the first year that all areas had name-based reporting.[9] All cases are reported to CDC without identifying information.

For most data analyses, national HIV surveillance reports follow conventions that place AA and NHOPI persons who are also Hispanic into the Hispanic/Latino category and persons reported as both AA or NHOPI and another reported race into the Multiple Races category.[9]

Medical Monitoring Project (MMP)

The Medical Monitoring Project (MMP) is a supplemental surveillance project designed to produce nationally representative data on people living with HIV infection, who are receiving care in the U.S.[17] Information is collected on clinical outcomes and behaviors of HIV-infected persons receiving care in the United States. Collection of data from interviews with patients with HIV provides information on current levels of behaviors that may facilitate HIV transmission; patients' access to, use of, and barriers to HIV-related secondary prevention services; utilization of HIV-related medical services; and adherence to drug regimens. Through abstraction of medical records, MMP also provides information on clinical conditions that occur in persons with HIV as a result of their disease or the medications they take, receipt of HIV care and support services, and the quality of these services.

National HIV Behavioral Surveillance System (NHBS)

The National HIV Behavioral Surveillance System (NHBS) is CDC's most comprehensive system for conducting behavioral surveillance among persons at highest risk for HIV infection in the United States.[18] The overall strategy for NHBS involves conducting rotating annual cycles of surveillance in 3 different populations at high risk for HIV: men who have sex with men, injection drug users and

heterosexuals at increased risk. Surveillance is conducted in 20 cities in the United States, which have high AIDS prevalence. NHBS collects detailed information on HIV risk behaviors, use of prevention services, and HIV testing.

Methods

As a first step, we conducted a literature review to determine demographic and HIV epidemiologic characteristics of AAs and NHOPIs, to identify gaps/barriers in HIV surveillance, and to explore ways to improve HIV surveillance for these populations. This was followed by consultations with experts from CDC and other federal agencies, academia, and partner organizations that work with AAs and NHOPIs. These activities informed the development of an HIV surveillance assessment tool and recommendations for effective HIV surveillance among AAs and NHOPIs in participating states. Finally, we held assessments with state HIV case surveillance and MMP/NHBS coordinators to gain insight into issues of data collection, analysis, dissemination, and use, and identify areas for improvement.

Summary of key findings

Consultations with internal and external partners

Consultations with experts and partner organizations revealed the following:

Data collection for AAs and NHOPIs

- The number of AAs and NHOPIs with HIV infection may be undercounted because of misidentification of race/ethnicity in medical records, which are the main source of information for case reports used in surveillance. Participants in the assessment indicated that medical record information does not necessarily reflect patient self-report or self-identification of race/ethnicity and is limited by the accuracy of the information obtained by providers. An example cited by many participants is the frequent misidentification of Filipinos as Hispanics/Latinos due to assumptions made based on Hispanic surnames.
- Many participants expressed concern that few states collect and report data on ethnic subgroups for AAs and NHOPIs (e.g., Chinese, Filipino, Vietnamese, etc.).
- There is a need for continued provider education on how to collect and document accurate race/ethnicity information for the purposes of HIV surveillance.
- Because a large proportion of AAs and NHOPIs are foreign-born, HIV surveillance programs should increase effort to collect country of birth data for immigrants. Information on country of birth can be used to corroborate categorization of race/ethnicity.
- Participants described a need to foster and strengthen partnerships between health departments and community-based organizations (CBOs) serving AA and NHOPI communities to improve data collection. CBOs serving AAs and NHOPIs may report AA and NHOPI race more accurately than do facilities that provide services to people, regardless of AA and NHOPI identity. For example, the Asian and Pacific Islander Wellness Center (A&PI Wellness Center), which is funded by the San Francisco health department to provide testing and counseling services, provides data that help to improve completeness of race and ethnic subgroup data for AAs and NHOPIs.

Data analysis and dissemination for AAs and NHOPIs

- Participants described the need for state health departments to discontinue combining AAs and NHOPIs into an "Other" category, which may include a mixture of American Indians, Alaska Natives, Asians, Pacific Islanders, and also cases with missing race/ethnicity information.
- Participants suggested that States in which AAs and NHOPIs constitute ≥5% of the total population

should be able to report data separately for AAs and NHOPIs and not combine or group them into an "Other" category.

Assessments with state HIV surveillance coordinators

Data collection for AAs and NHOPIs

Some participants raised concern about misclassification of race/ethnicity for AAs and NHOPIs, which may contribute to underestimation of cases of HIV. For example, Filipinos with Hispanic names may be misidentified as Hispanic/Latino.

Almost all the participating jurisdictions routinely match HIV surveillance data with TB registries to identify co-infection with TB. Fewer jurisdictions match HIV surveillance data with viral hepatitis registries to identify persons who are co-infected with viral hepatitis

All participating jurisdictions have policies stipulating the need to collect accurate and timely HIV data on all racial/ethnic groups. For the National HIV surveillance system, Hawaii developed an addendum to the CDC HIV confidential case report form that includes a section to collect information on 26 ethnic subgroups for AAs and NHOPIs. San Francisco and LA counties also collect ethnic subgroup data for AAs and NHOPIs.

NHBS and MMP collect race/ethnicity data according to OMB standards as specified in the primary instrument. However, they do not collect ethnic subgroup data.

Since HIV case surveillance captures race/ethnicity information that is typically documented by providers, there is a concern that lack of cultural awareness may affect the determination and recording of race/ethnicity information for AAs and NHOPIs, contributing to underreporting of HIV. Furthermore, participants from some jurisdictions believe that difficulties with language and concerns about stigma may be barriers for some AAs and NHOPIs to seeking HIV testing services and care and this may contribute to underestimating the true burden of HIV in these populations.

Data analysis and presentation for AAs and NHOPIs

Categorization of AAs and NHOPIs in surveillance publications is typically determined by the overall numbers of cases among these populations. Many jurisdictions do not have large numbers of HIV cases among AAs and NHOPIs to consider these groups separately and so they are grouped into an "Other" category for data presentation. Reporting on small numbers of cases may compromise confidentiality and estimates calculated from small numbers may be unreliable. For routine surveillance publications, the majority of jurisdictions use the combined AA/NHOPI category. Los Angeles uses the combined category as well when displaying data in tables, but adds a footnote which details the number of cases by ethnic subgroups within the AA and NHOPI populations within the bounds of their data release guidelines. Additionally, in response to special requests, Los Angeles provides AA and NHOPI ethnic subgroup data. For special requests concerning NHBS and MMP data, some jurisdictions treat AAs and NHOPIs separately in accordance with their data release policies.

Prior to September 2010, San Francisco reported data for AAs and NHOPIs at the ethnic subgroup level, but due to small numbers and lack of requests for reports at this level, they no longer routinely report data for ethnic subgroups. The jurisdiction currently reports data using the combined AA/NHOPI categories, but when they receive special requests, the data are provided at the ethnic subgroup level in accordance with their data release guidelines.

Hawaii, where approximately 60% of the population consists of AAs and NHOPIs, routinely reports race/ethnicity data at the ethnic subgroup level (i.e., Hawaiian, other NHOPI, Japanese, Filipino, other Asians).

Dissemination of data on AAs and NHOPIs

HIV surveillance data are disseminated in a variety of ways, including routine surveillance reports; epidemiologic profiles; newsletters; slide sets posted on health department websites; fact sheets; publications in

journals; and presentations to HPGs, CBOs, providers, and at conferences. Jurisdictions also provide specific data on request. HIV surveillance data are disseminated in accordance with the jurisdictions' data release policies to ensure that confidentiality is not compromised and that the data are reliable.[19]

Use of AA and NHOPI surveillance data

Surveillance data on AAs and NHOPIs are used to understand the burden and distribution of HIV in these populations and to plan for prevention and care programs, as well as evaluate these programs. The data are also used by HPGs and AA/NHOPI-focused CBOs to support funding applications for prevention and care services and by health departments for prevention activities, including initiating partner services.

Recommendations

According to the Federal Implementation Plan of the NHAS, CDC is tasked with making recommendations to state health departments for effective HIV surveillance among AAs and NHOPIs. Based on the findings of the assessment and recognizing that some approaches may be applicable in some jurisdictions but not others, we propose recommendations that should be standard practice to improve HIV surveillance among AAs and NHOPIs. We also propose recommended practices that expand on these basic improvements to be implemented where possible.

1. Improve data collection for AAs and NHOPIs

Standard practice:

- Collect data on ethnic subgroups of AAs and NHOPIs (e.g., Chinese, Vietnamese, Hawaiian) in addition to data on race. All HIV surveillance programs already collect race/ethnicity data, including that on AAs and NHOPIs, according to OMB directives. Reporting data by AA and NHOPI ethnic subgroups allows for targeting prevention resources to specific populations. Strategies to facilitate this could include flagging all cases initially reported as AA or NHOPI for follow-up to characterize their ethnic subgroups.
- Educate providers on the importance of collecting self-reported information about race and ethnic subgroup for AAs and NHOPIs.

Recommended practice:

- Match HIV surveillance data with viral hepatitis and TB registries in order to identify co-infection with hepatitis B and TB since both are prevalent among AAs and NHOPIs.

2. Improve analysis and presentation of data for AAs and NHOPIs

Standard practice:

- Analyze and report data on AAs and NHOPIs separately in routine and special reports ensuring that confidentiality is not compromised and that the data are reliable. Also, present data by ethnic subgroups for these populations when feasible. When numbers of cases are small, strategies can include:
  - » combine data for multiple years,[20] or
  - » pool data for regional analyses (e.g., Washington State, Oregon, California)
- Present data for AAs and NHOPIs separately from large populations using a scale appropriate for small populations when data for larger population groups might overshadow the data on AAs and NHOPIs in the same chart.[10]

3. Improve dissemination of AA and NHOPI surveillance data

Standard practice:

- Distribute surveillance reports, epidemiologic profiles, factsheets, and newsletters containing data on AAs and NHOPIs to CBOs serving

AA and NHOPI communities, as well as other organizations that have expressed a need for information on AAs and NHOPIs.

- Respond quickly to special data requests related to AAs and NHOPIs.

Recommended practice

- Post surveillance reports, epidemiologic profiles, factsheets, newsletters, and slide sets containing data on AAs and NHOPIs on the health department's website.

4. Improve use of AA and NHOPI surveillance data

Standard practice:

- Conduct presentations to HPGs, Ryan White Planning Councils, other planning bodies, as well as AA and NHOPI-focused CBOs that use HIV data for prevention and evaluation, including assessing linkage to care, retention in care, and viral suppression.

- Promote the use of AA and NHOPI surveillance data by providing technical assistance to HPGs and AA/NHOPI-focused CBOs in interpreting the data and using the data to prioritize risk groups for prevention and care programs

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